

The New Institutions: Last Ditch Arguments

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Abstract: A recent position taken by some mental retardation professionals poses a threat to the major gains made during the last two decades on behalf of mentally retarded persons. Their position holds that a substantial number of currently institutionalized persons are sub-trainable and should be assigned to enriched (institutional) living environments. This article refutes their ill-founded position through a brief review of national trends and a recent analysis of Nebraska's institutionalized mentally retarded population. This analysis clearly demonstrates that, given adequate and appropriate community-based alternatives, virtually all of Nebraska's—and the nation's—institutionalized, mentally retarded population can grow and develop in least restrictive, community alternatives.

Mental retardation professionals have provided strong leadership in achieving major gains on behalf of mentally retarded people during the past two decades. In this process a high degree of consensus has evolved on the importance of the ideology of normalization and community-based services in enhancing the quality of life and the developmental growth of all mentally retarded citizens.

Now these gains and this consensus are being threatened by a report issued by a group of professionals who, ironically, include individuals who have contributed significantly to these developments in the field of mental retardation. This danger surfaced recently in the form of a report by the Partlow Review Committee (Ellis, Balla, Estes, Hollis, Isaacson, Orlando, Palk, Warren, Siegel, 1978), to the U.S. District Court in the case of *Wyatt v. Hardin* (1978). Partlow is a residential institution in Tuscaloosa, Alabama, serving approximately 925 mentally retarded individuals; *Wyatt v. Hardin* (1978) is the legal case in which the conditions within this facility are being contested. The report, composed by the nine mental retardation professionals on the committee, purports to explain the failure of the Partlow State School in meeting modern treatment standards mandated by the court in the original *Wyatt* decision.

The Partlow Review Committee reached the following conclusions included in the Ellis, et al. (1978) memorandum:

1. that the growth potential for a substantial number of Partlow residents is so low that training programs seem inappropriate "even for living within the sheltered environment of the institution" (p. 4);
2. that persons who are not trainable should be assigned to programs for enriched daily programs (p. 7);
3. that community living is a "serious injustice" for most Partlow residents who are unable to live adequately outside a highly sheltered environment such as the institution (p. 4).

There are many objections that can be made to these recommendations to essentially classify most Partlow residents as subtrainable and abandon training and education efforts on their behalf. Some of these objections are:

1. Such classifications generate self-fulfilling prophecies of client failure.
2. This grouping violates the long established principle of individualization upon which individualized programming is based.
3. The approach facilitates the phenomenon of blaming the client as an explanation for poor or inefficient programs.
4. This poor prognostication for the residents of Partlow is an opinion, not a research finding. Indeed, modern applied research clearly demonstrates this to be false (Berkson & Landesman-Dwyer, 1977).
5. These predictions ignore the intent of the developmental model, as well as new technologies of training for severely and profoundly mentally retarded persons.
6. Such a recommendation runs counter to the constitutional principle that the coercive segregation of individuals from community life is justifiable only on overriding evidence that public safety requires such segregation.

In short, the Partlow Review Committee's recommendations portend not only a lower level of humane and individualized care, but also a stagnation in the technologies and treatments necessary to most effectively enhance the lives of these and all mentally retarded citizens.

Abundant research is now available to support the following facts: (1) institutionalization frequently has destructive consequences (Blatt, 1973; Blatt, & Klaplan, 1966; Flint, 1966; Goffman, 1966; Halderman v. Pennhurst, 1977; Taylor, 1977); (2) appropriate community-based residential settings are generally more beneficial than institutional placements (Ferleger & Boyd, 1979; Gilhool, 1978; Kushlick 1976); (3) mentally

retarded people with a wide spectrum of disabilities—including severely and profoundly mentally retarded people—can be successfully served in community-based settings (Biklen, 1979; Bogdan & Taylor, 1976; Dybwad, 1978; Edgerton & Bercovici, 1976; Gollay, Friedman, Wyngarde & Kurtz, 1978; Menolascino, 1977; Tizard, 1969).

Despite this and other impressive evidence, the Partlow Committee concluded that "most residents now in Partlow will not be able to adequately live outside a highly sheltered environment such as an institution (Ellis, et al., p. 17).

This article will (1) explore this "new institution" position, (2) refute its principal contention that today's institutionalized population is "sub-trainable" and belongs in "enriched" institutional settings, and (3) point toward future directions in bringing about the establishment of total community integration.

The New Institution

Institutional proponents have apparently forgotten that regulation, accreditation and massive amounts of money were supposed to have made the difference between institutions being places of abuse and neglect versus places of growth and development. In most instances this has not occurred. For example, in an evaluation of accreditation survey data from 48 state mental retardation facility surveys performed in 21 states, 35 facilities failed this critical minimal test of treatment quality (Braddock, 1977). Those not accredited failed primarily for the following reasons:

1. the excessive use of chemical restraint and physical seclusion;
2. the impersonal nature of the physical environment;
3. excessive crowding of residents in living space;
4. the failure to provide comprehensive, interdisciplinary initial and periodic evaluation, program planning, follow-up in relation to educational needs or rehabilitative needs, as well as a general lack of developmental services;
5. the lack of the use of direct care personnel in training residents in self-help skills; and
6. the failure to employ sufficient numbers of qualified personnel in direct care service, dentistry, education, nursing, physical and occupational therapy, psychology, recreation, social services, speech pathology and audiology, and vocational training.

These deficiencies are not the result of minor mismanagement that can be eliminated by pouring in more money. Newer buildings and more manpower have not eradicated the elements which make up the very nature of an institution: isolation, removal

from ongoing public and professional scrutiny, segregation, depersonalization, and in the worse cases, direct abuse of the residents. Nor should these deficiencies be blamed on the nature of those who reside in today's institutions.

It should be noted that 13 institutions were accredited. Thus, a small percentage of institutions were able to meet their minimal standards for humane care and treatment. There is no intent to portray the thousands of professionals and paraprofessionals who work in institutions as inhumane. Indeed, most are dedicated to serving the residents of institutions. In many states there are not yet viable alternatives to large congregate-care facilities. The intent is to indicate that—given the development of viable community alternatives—most mentally retarded persons grow and develop in settings that are characterized by developmental programming and community integration. Our nation is in the process of change relative to our care and treatment of mentally retarded citizens. While there are mentally retarded persons in institutions, it is clearly our obligation to focus our attention on ensuring the best possible services in institutional settings while at the same time focusing our primary attention on the development of community alternatives.

Characteristics of Those Who Are in Institutions

Institutional proponents base their position on the false premise that a substantial number of currently institutionalized mentally retarded persons are *sub-trainable*. But what are the needs of those who are housed in today's institutions? Are they *sub-trainable* and doomed to lifelong custodial care?

The Partlow Report gives a misleading posture relative to *who* resides in today's institutions. The report holds that a substantial number of that institution's residents have such a low potential for growth that training programs seem inappropriate and that those residents should be assigned to *enriched* daily living programs. This unfortunate view is clearly contradicted by a study of the basic needs of Nebraska's institutionalized mentally retarded population (*Horacek v. Exon*, 1978). It is important that today's professionals and advocates understand who resides in today's institutions. The Nebraska data strongly indicate the 873 mentally retarded persons in the state's institutions are not persons who should be doomed to lifelong custodial care. The Nebraska study is offered as a refutation of the Partlow Report.

The Nebraska study shows that of the state's 873 institutionalized mentally retarded persons, only 74 have major medical or major behavioral needs. A person with major to moderate medical support needs is defined as requiring immediate medical back-up support. A person with major behavioral needs is defined as generally requiring a very structured, intensive, behavior change-oriented environment with a 1:1 staff-to-client ratio. The large majority of institutionalized persons, however, would present no major problems relative to their placement in community-based alternatives given adequate resources and support. In fact, Nebraska's community-based programs currently serve a population as complex as those found in the institution (Eastern Nebraska Community Office of Retardation, 1979). In the opinion of the Nebraska institution's medical staff only eight institutionalized mentally retarded persons require medical services not typically provided in the state's community-based mental retardation programs (Touche Ross and Company, 1980). The same report concludes that all other institutionalized persons with special medical needs could be adequately and appropriately served in community-based programs given: (a) the proximity of appropriate medical services, (b) special training for residential and day program staff, (c) barrier free facilities, and (d) additional staffing to assist in self-care, ambulation and positioning.

It is the areas of behavioral and developmental needs that can generally be surprisingly and favorably dealt with through specific, individualized programming contrary to the Partlow Committee's posture. Experience has shown that people with similar needs in community settings typically attain many of these skills after consistent exposure to developmental programming. In fact, the Touche Ross report (1980) states that the amount of direct care (developmental) services in community programs in Nebraska for the most severely involved is approximately 42 hours per week as opposed to the institutions 21-32 hours per week. Thus, the highest-need mentally retarded persons receive more developmental services in community programs than in the institution. Even those who do not attain all these skills can still be supported in community settings in a humane and dignified manner. Confirmation of this goal is the fact that Nebraska has virtually eliminated new admissions of mentally retarded persons into institutions. In 1979 there were only ten children less than six years of age and only 240 school-age children in Nebraska's institutions. Of these, more than 66% were in their late adolescent years. Early identification, early

intervention, in-home supports, parent training, etc., have eliminated the need for institutionalization in all but the rarest instances. In fact, one of the most powerful forces in deinstitutionalization in Nebraska has been the virtual halt of new admissions to the institution.

Those who are institutionalized in Nebraska are the middle-aged mentally retarded persons who had no other alternatives in previous decades. They were placed there when there were no community alternatives, when rights had not yet been articulated and when families had no alternatives. These alternatives exist today in Nebraska's community programs. Thus, placement into less restrictive alternatives is mandatory.

These data contrast sharply with the Partlow conclusions and other institutional statistics. The *new* institution is skilled in employing resident data designed to justify the institution's existence. A repeated false assumption is that the more severely mentally retarded the population, the greater the need for an institution. To exaggerate needs, the *new* institution uses mono-evaluations, i.e., so many blind, deaf, orthopedically handicapped residents and so many mildly, moderately, severely and profoundly mentally retarded residents. *New* institution proponents use such labels—rather than describe developmental needs—in an apparent attempt to shock the public into the false conclusion that persons with such labels cannot be served through their families, communities, or both.

The fact of the matter is that the institutional population is a complex and challenging population but it is not the type described by pro-institutional proponents. The large majority are neither medically fragile nor behaviorally violent. The past two decades of applied research clearly demonstrate all mentally retarded persons are capable of growth and development. All are sentient human beings who can learn (Berkson & Landesman-Dwyer, 1977). This includes those residing in today's institutions.

Alternatives to Institutions for Severely Involved Persons

"We cannot make the assumption that by dumping these individuals out of the institutions, the community will somehow assume its responsibility and will begin to treat them like human beings. . . . Communities have herded 'de-institutionalized' persons into a wide variety of equally restrictive or more restricted environments . . ." (Leland, 1981). There is much ignorance both on the side of pro-institutional advocates and pro-

community advocates about the nature of community-based alternatives. Unfortunately, the act of deinstitutionalization has at times been synonymous with dumping, that is, the act of blindly moving persons out of institutions into any place that could house them in the community regardless of individual needs. Dumping often occurs into such places as nursing homes, board and room homes, and hotels for transients, etc.

Dumping is deinstitutionalization only in the sense that it reduces the numbers of people in state institutions. However, it is clearly not the placement of mentally retarded persons into less restrictive environments that meets their basic human and developmental needs. True deinstitutionalization is not the mere reduction in the number of persons residing in institutions, rather it is the individualized placement of each mentally retarded person into a community-based service delivery system which ensures the physical, spiritual and developmental well-being of the mentally retarded person during the individual's lifespan. It is the guarantee of an array of residential, educational, vocational and leisure time services based on each mentally retarded person's needs.

Pro-community proponents give credence to many pro-institutional arguments by blindly denying the complexity of developing alternatives to institutions, by denying that some placements out of institutions have been at best trans-institutionalization (for example, placements into nursing homes), by ignoring the fact that some *dumping* has occurred (for example, into psychiatric ghettos), and by excessively downplaying the fact that alternatives are sometimes as costly or even occasionally *more* costly than institutional placements. For example, the brief of the *Amici Curiae* to the Supreme Court of the United States in the *Pennhurst* case recently held that no dumping has occurred throughout the nation and community placements always cost less than institutional care (*Halderman v. Pennhurst*, 1980). Often the pro-community alternative development process is automatic. Such a facile approach inevitably results in trans-institutionalization and dumping. Menninger (1980) succinctly summarizes the responsibility of community alternative proponents when pointing out in a recent study that the movement toward community services must be based on as solid empirical ground as possible, for failure to develop excellent and accountable community-based services would most surely result in another era of institutions.

Our data and experiences indicate that for those mentally retarded persons with more complex be-

havioral, medical and developmental needs the *new* institution is not necessary. Deinstitutionalization is a function of the development of adequate and appropriate community-based services. This does not mean that all institutionalized persons can immediately move directly into their communities. Adequate and appropriate alternatives still must be developed in most communities across the nation. Community-based alternatives must be able to ensure mentally retarded persons and their families that there will be:

1. a variety of community-based less restrictive options utilizing modern treatment and programmatic techniques in small dispersed residential, educational, vocational and leisure-time services;
2. maximum parental input while still ensuring individual client rights;
3. ongoing internal and external monitoring of the quality of services;
4. a realistic cost per person for services, and assurance that program financing will be ensured across time; and
5. prudent risk for all mentally retarded citizens as they live, work and play in communities, while at the same time safe-guarding each person as much as necessary.

Community programs can adequately, appropriately, and developmentally serve even the most severely involved mentally retarded children and adults. Nebraska's ENCOR and Michigan's Macomb-Oakland programs demonstrate this fact (Menolascino, 1977; Biklen, 1979). Services for the most severely involved clients can be characterized in the following manner:

1. they are concrete, comprehensive, replicable, development-oriented programs;
2. they are ensured across the person's lifespan based on the degree and intensity of services required by each individual;
3. they are small, no more than six to eight persons being housed in any given setting;
4. the various programs and services are dispersed throughout the community and state in a well-managed service delivery system;
5. manpower resources are derived from and trained in the local community with adequate medical and psychiatric back-up personnel.

Barriers to Movement

If the vast majority of those who are housed in institutions are not there because of their personal needs, one would then wonder why they *are* there. There are several barriers which impede the movement of people out of institutions and which contribute to their placement into institutions:

1. There are several persistent inter-related misconceptions about who is currently institutionalized. These misconceptions have been examined previously. Their effect, if allowed to spread, would be to undermine efforts to create community-based alternatives and to make institutionalization appear as an accepted course of action.

2. There are also related misconceptions about who can be served in community programs. Quality community programs can serve nearly anyone who is currently institutionalized, given re-distribution of money, manpower, and management systems and, more importantly, a national renaissance that underscores the human and legal rights of all citizens.

3. There are several misconceptions about what does constitute appropriate community-based alternatives to institutions. They are not mini-institutions. They cannot be dumping grounds. They must be small, dispersed and developmentally-oriented environments which ensure adequate and appropriate services across each person's lifespan.

4. Finally, there is a myriad of federal and state social policies and funding mechanisms which promote incentives to institutionalization, trans-institutionalization and dumping, while at the same time providing disincentives to the development of modern community alternatives.

The movement of mentally retarded citizens from institutional environments to community-based alternatives requires the concomitant movement of some of the resources currently allocated to institutions. In other words, it costs money to support persons in their communities and in their families. The hundreds of millions of dollars that are spent in today's *new* institutions must be redistributed as the people move into community and family life. This financial reality, the need for money to follow the client from the institution to the community, was underscored as early as 1970 by the President's Committee on Mental Retardation (Cook, 1970). As the mentally retarded are integrated into community systems of care, so too must the financial resources be redistributed. Community-based programs have demonstrated themselves to be cost-effective when compared to institutional costs. For example, in 1978-79 Nebraska's community-based programs serving a similar population spent slightly more than \$8,000 per year per person as compared to \$23,500 per year per person in Nebraska's state institutions for the mentally retarded (Horacek v. Exon, 1978). More importantly, our professional and societal postures toward mentally retarded persons must be unified so the Catch 22 of today's social policies and financial outlays can be resolved in a positive fashion. Society cannot ensure some of its mentally retarded citizens community integration while millions of dollars continue to be spent to

institutionalize their mirror images in *enriched* institutions (Rothman, 1979).

Conclusion

The overwhelming majority of mentally retarded persons who currently reside in our nation's institutions are not there because of some exotic need related to their disability. All mentally retarded persons are capable of growth and development. The professional posture that some mentally retarded citizens are *subtrainable* and hence need to reside in *enriched* institutional settings for the rest of their lives is an archaic one contradicted by the major ideological and programmatic developments of the last two decades (Menolascino, 1977). Currently institutionalized mentally retarded persons are there because of archaic professional views that persistently support social policies designed to maintain institutions regardless of the demonstrable needs and potentials of the mentally retarded persons residing therein. The *new* institution has taken on a new language, a new look and new management neologisms; yet it is still a system that generally dehumanizes and depersonalizes its residents in the same Procrustean bed. Yet we should take heart that communities across our country are serving mentally retarded persons of all levels of need in spite of the array of regressive professional postures and social policies noted above. Parents and professionals, as well as the mentally retarded themselves, must push for further public and professional education to help support the rapidly emerging national policies that are based on the normalization principle, the right to treatment, the right to the least restrictive setting, and the developmental aspects of community-based service systems which enhance the person, the family and the community. These emerging social policies must stress, for families and mentally retarded citizens themselves, a continuum of service choices. These choices, contrary to *enriched environment* proponents, must accept all mentally retarded persons as developmental beings and must utilize state of the art techniques to ensure maximum growth and development.

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